



**\*\* PROGRAM SUBJECT TO CHANGE \*\***  
**ALL SESSION TIMES ARE MOUNTAIN TIME ZONE**

| DAY             | TIME               | SESSION   | SPEAKER  | SESSION TYPE/LOCATION            |
|-----------------|--------------------|---|--|----------------------------------|
|                 |                    |   |  |                                  |
| Friday-Monday   | Fri: noon-9pm      | Registration/Help Desk  | IRSF Staff and volunteers                            | Promenade Level Foyer            |
|                 | Fri: 5p-9p         | Bookstore: Awareness items, educational materials. (Silent Auction tables setup Friday through Saturday Tribute Reception only) |  | Boardroom                        |
|                 | Sat: 7:30a-7:30p   |   |  |                                  |
|                 | Sun: 7:30a-5:30p   |   |  |                                  |
|                 | Mon: 8a-noon       |   |  |                                  |
|                 |                    |   |  |                                  |
| Saturday-Sunday | 9am-5pm            | Exhibitors and Information Booths: Assistive technology, adaptive equipment, fundraising, clinics and more                      | Exhibitors and IRSF staff                            | Promenade Level Foyer area       |
|                 | Session hours only | Respite Program   |  | Shoshoni and Manitou             |
|                 |                    |   |  |                                  |
| Friday May 28   | 9am-noon           | Barn Tour: Pikes Peak Therapeutic Riding Center   | See Concierge desk for map and details               |                                  |
|                 | Noon-9p            | Registration open   | IRSF Staff   |                                  |
|                 | 6pm-10pm           | Dinner  | At your leisure                                      | Mountain View Restaurant         |
|                 | 7pm                | Welcome and Orientation   | Paige Nues, Director, Family Support, IRSF           | Colorado Ballroom                |
|                 |                    | Welcome Address   | Mickie McCool, Conference Planning Committee, Parent | Colorado Ballroom                |
|                 | 8pm                | Crackerbarrels: Hopes and Expectations  |  |                                  |
|                 |                    | 3 yrs and under   | Katie Guernsey and Joey Razzano                      | White River I                    |
|                 |                    | 4 - 7 yrs   | Emilie Rabke and Deberah Patterson                   | White River II                   |
|                 |                    | 8 – 16 yrs  | Cordelia Albanese and Shannon Stoiber                | Cheyenne I                       |
|                 |                    | 17 yrs and over   | Clifford and Judy Fry                                | Cheyenne II                      |
|                 |                    | Grandparents  | Diane Ross and Jennifer Endres                       | Executive Press Room/Ampitheater |
|                 |                    | Rettnetters and Facebookers   | Shirley Hurlburt                                     | Comanche                         |

|                        |              |   |   |                                 |
|------------------------|--------------|---|---|---------------------------------|
|                        |              | CDKL5/Atypical Rett Professionals   | Katheryn Elibri Frame<br>Will Rabke   | Ute<br>Kiowa                    |
|                        |              |   |   |                                 |
| <b>Saturday May 29</b> | 6:30a-10:30a | <i>Breakfast</i>  | <i>At your leisure</i>  | <i>Mountain View Restaurant</i> |
|                        | 8a           | Rett Syndrome 101   | Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Birmingham Civitan International Research Center</i>   | Colorado Ballroom               |
|                        | 8:30a        | Genetics 101  | Steve Skinner, M.D., <i>Director Clinical Genetics Services, Greenwood Genetic Center</i>   | Colorado Ballroom               |
|                        | 9am          | Keynote: The Power of the Powerless   | Susan Zimmermann, author <i>Keeping Katherine</i>   | Colorado Ballroom               |
|                        |              |   |   |                                 |
|                        | 9:30a        | <i>Break</i>  |   | <i>Foyers</i>                   |
|                        |              |   |   |                                 |
|                        | 9:45a        | What's Going Right in the Brain   | Aleksandra Djukic, M.D., Ph.D. <i>Director, Rett Syndrome Center, Albert Einstein College of Medicine at Montefiore</i>   | Colorado Ballroom               |
|                        | 10:10a       | Apraxia and Communication   | Linda Burkhart, <i>Simplified Technology</i>  | Colorado Ballroom               |
|                        | 10:55a       | Enhancing Communication: Regulating Sensory Input and Supporting Ease of Access               | Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i>   | Colorado Ballroom               |
|                        | 11:40a       | An Integrated Model of Communication and Literacy Instruction for Students with Rett Syndrome | Pati King-deBaun, M.S. CCC-SLP, <i>Creative Communicating</i>   | Colorado Ballroom               |
|                        |              |   |   |                                 |
|                        | 12:15pm      | <i>Lunch</i>  | <i>Mountain View Restaurant Hours 11am – 2pm</i>  | <i>Mountain View Restaurant</i> |
|                        |              |   |   |                                 |
|                        | 1:15pm       | Well Child and Adult Care Overview  | Jane Lane, RN, <i>University of Alabama Birmingham Rett Center and IRSF</i>   | Colorado Ballroom               |
|                        | 1:40pm       | Neurology for Rett Syndrome   | Daniel G. Glaze, M.D. <i>Professor, Departments of Pediatrics and Neurology Baylor College of Medicine Medical Director, The Blue Bird Circle Rett Center Chief, The Rett Clinic, Texas Children's Hospital Chief, Texas Children's Hospital Sleep Clinic</i> | Colorado Ballroom               |
|                        | 2:15pm       | Gastroenterology for Rett Syndrome  | Kathleen Motil, M.D., Ph.D. <i>Pediatrician and Gastroenterologist, Blue Bird Rett Center BCM, TCH</i>  | Colorado Ballroom               |
|                        | 2:45pm       | Orthopedics and Scoliosis   | John Killian, MD, <i>Orthopedics for Kids</i>   | Colorado Ballroom               |
|                        | 3:15pm       | Importance of Therapies   | Aloysia Schwabe, M.D., <i>Physical</i>  | Colorado Ballroom               |

|                          |                    |   |   |  |
|--------------------------|--------------------|---|---|--|
|                          |                    |   | <i>Medicine and Rehabilitation,<br/>Blue Bird Rett Center, BCM,<br/>TCH</i>   |  |
|                          |                    |   |   |  |
|                          | 3:45pm             | <i>Break</i>  |   | <i>Foyers</i>  |
|                          |                    |   |   |  |
|                          | 4pm                | Research and Clinical Trials  | Tony Horton, PhD, <i>IRSF</i> and<br>Jeffrey Neul, MD, PhD, <i>Baylor<br/>College of Medicine</i>   | Colorado Ballroom  |
|                          | 5pm                | Importance of Raising<br>Awareness and Funds:<br><i>Research to Reality</i><br>Campaign and a \$1M Dollar<br>Match            | Steve Bajardi, Executive<br>Director, <i>IRSF</i>   | Colorado Ballroom  |
|                          |                    |   |   |  |
|                          | 6p-10p             | <i>Dinner</i>   | <i>At your leisure</i>  | <i>Mountain View<br/>Restaurant</i>                      |
|                          |                    |   |   |  |
|                          | 7:30p              | Tribute Reception and<br>Auction  | Hosted by <i>IRSF</i>   | Centennial<br>Ballroom (Main<br>Lodge Entry Level)       |
|                          |                    |   |   |  |
| <b>Sunday<br/>May 30</b> | 6:30am-<br>10:30am | <i>Breakfast</i>  | <i>At your leisure</i>  | <i>Mountain View<br/>Restaurant</i>                      |
|                          |                    |   |   |  |
|                          | 8am -<br>noon      | <i>Partner-Assisted Scanning<br/>with PDD Communication<br/>Books: Strategies for<br/>Children who have Rett<br/>Syndrome</i> | Linda Burkhart, <i>Simplified<br/>Technology</i>  | <i>Workshop<br/>Executive Press<br/>Room/Ampitheater</i> |
|                          |                    |   |   |  |
|                          | 8am                | The Enriched Environment: A<br>Model for Conversation with<br>Schools and Others  | Dr. Mary Jones, <i>Director, Katie's<br/>Clinic for Rett Syndrome,<br/>Oakland Children's Hospital &amp;<br/>Research Institute</i>   | White River I  |
|                          |                    | PT/OT   | Mike Binet, PT and Margaret<br>Spring, OT, <i>Children's Hospital<br/>Denver</i>  | Cheyenne II  |
|                          |                    | The Maturing Woman with<br>Rett Syndrome: From<br>Puberty to Menopause  | Jane Lane, BSN, RN, <i>University<br/>of Alabama Birmingham Rett<br/>Center and IRSF</i>  | Cheyenne I   |
|                          |                    | Clinical Features and Current<br>Research: CDKL5 and<br>Atypical Rett Syndrome  | Jeffrey Neul, MD, PhD, <i>Baylor<br/>College of Medicine</i> and Dr.<br>Katheryn Elibri Frame, <i>president<br/>of the International Foundation<br/>for CDKL5 Research (IFCR)</i> | Colorado Ballroom  |
|                          |                    |   |   |  |
|                          | 9am                | Getting Started Visual<br>Supports and Book Reading.<br>Who? What? How? and<br>When?  | Pati King-deBaun, M.S. CCC-<br>SLP, <i>Creative Communicating</i>   | White River II   |
|                          |                    | Would Counseling Help?  | Robert Furey, Ph.D.   | Cheyenne II  |
|                          |                    | Cognitive and IEP<br>assessment tools 101   | Dr. Terry Katz, <i>University of CO<br/>School of Medicine</i>  | White River I  |
|                          |                    | Nutritional Management of   | Marilyn Stevenson, RD, CSP  | Colorado Ballroom  |

|  |         |   |  |                                  |
|--|---------|---|--|----------------------------------|
|  |         | Children with Rett Syndrome   | and Margaret Spring, OT, <i>Children's Hospital Denver</i>   |                                  |
|  |         | Roundtable Discussion: Once She's Grown Up and Out of School                        | Clifford and Judy Fry  | Cheyenne II                      |
|  |         |   |  |                                  |
|  | 10am    | Climbing the "Eye Gaze Technology" Mountain: Steps for Conducting Successful Trials | Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital &amp; Research Institute</i> | White River I                    |
|  |         | PT/OT   | Mike Binet, PT and Margaret Spring, OT, <i>Children's Hospital Denver</i>  | Cheyenne II                      |
|  |         | Accessing the General Education Curriculum  | Mick Ross, MS and Diane Ross, MS, LCPC, <i>Educators and Parents</i>   | Cheyenne I                       |
|  |         | Fundraising: A "How-To" Workshop  | Jennifer Endres, <i>IRSF</i>   | Colorado Ballroom                |
|  |         | Nutritional Management of Children with Rett Syndrome                               | Marilyn Stevenson, RD, CSP, <i>Children's Hospital Denver</i>  | White River II                   |
|  |         |   |  |                                  |
|  | 11:10a  | Sibling Panel   | Nakisha Whittington  | Colorado Ballroom                |
|  | 11:50a  | Dad's Panel   | Jeff Huisinigh   | Colorado Ballroom                |
|  |         |   |  |                                  |
|  | 12:30pm | Lunch   | <i>Mountain View Restaurant Hours 11am – 2pm</i>   | <i>Mountain View Restaurant</i>  |
|  |         |   |  |                                  |
|  | 1:30pm  | Your Journey Through an Eight Step Special Needs Planning Program                   | Mary Anne Ehler, <i>Protected Tomorrows</i>  | White River II                   |
|  |         | Communication Goals for the IEP   | Linda Burkhart, <i>Simplified Technology</i>   | Executive Press Room/Ampitheater |
|  |         | Fundraising: A "How-To" Workshop  | Jennifer Endres, Family Resource Manager, <i>IRSF</i> and Jenni Grammer, Special Events Program Manager, <i>IRSF</i>             | Colorado Ballroom                |
|  |         | The Transition to Adulthood and Community Programs                                  | Laura Marshall, M.A., <i>University of Colorado at Colorado Springs</i>  | Cheyenne II                      |
|  |         | Implementing Effective Inclusive Practices  | Robin Brewer, <i>University of Northern Colorado</i>   | White River II                   |
|  |         |   |  |                                  |
|  | 2:30p   | Fostering Friendships: Toddlers to Teens  | Diane Ross, MS, LCPC, <i>Educator, Therapist and Parent</i>  | Cheyenne I                       |
|  |         | Hippotherapy  | Nancy Beers, Program Director and Amanda Delizzio, OT, <i>Pikes Peak Therapeutic Riding Center</i>                               | Cheyenne II                      |
|  |         | Getting Started Visual Supports and Book Reading. Who? What? How? and When?         | Pati King-deBaun, M.S. CCC-SLP, <i>Creative Communicating</i>  | White River II                   |
|  |         | Climbing the "Eye Gaze Technology" Mountain: Steps for Conducting Successful Trials | Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i>                          | White River I                    |
|  |         | Research Q&A  | Alan Percy, MD, <i>Director UAB Rett Center at the University of</i>   | Colorado Ballroom                |

|                      |        |   |   |                                  |
|----------------------|--------|---|---|----------------------------------|
|                      |        |   | <i>Alabama Birmingham Civitan International Research Center and Jeffrey Neul, MD, PhD, Baylor College of Medicine</i> |                                  |
|                      | 3:30pm | Break   |   |                                  |
|                      | 4pm    | Your Journey Through an Eight Step Special Needs Planning Program   | Mary Anne Ehler, <i>Protected Tomorrows</i>   | White River I                    |
|                      |        | Art Therapy   | Karla Trapp, <i>Art Alchemy</i>   | Colorado Ballroom                |
|                      |        | Becoming a Reader: Literacy Strategies from an Integrated Model of Communication Instruction.                             | Pati King-deBaun, M.S. CCC-SLP, <i>Creative Communicating</i>   | White River II                   |
|                      |        | Recreational Possibilities for Your Child with Rett Syndrome  | Beth Fox, Operations Manager, <i>National Sports Center for the Disabled (NSCD)</i>                                   | Cheyenne I                       |
|                      |        | Writing SMART IEP Goals   | Terry Wise, MA Special Education and Administration   | Cheyenne II                      |
|                      | 5pm    | Successful Integration of an Eye-Controlled Communication Device into Conversations at Home, School, and in the Community | Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i>               | White River I                    |
|                      |        | Would Counseling Help?  | Robert Furey, Ph.D.   | Cheyenne I                       |
|                      |        | 1:1 Consults with the IRSF Fundraising Team ( <i>signups taken at the IRSF Fundraising Exhibitor booth</i> )              | Jennifer Endres, Family Resource Manager, <i>IRSF</i> and Jenni Grammer, Special Events Program Manager, <i>IRSF</i>  | Colorado Ballroom                |
|                      |        | Writing SMART IEP Goals   | Terry Wise, MA Special Education and Administration   | Cheyenne II                      |
|                      |        | Implementing Effective Inclusive Practices  | Robin Brewer, <i>University of Northern Colorado</i>  | White River II                   |
|                      | 6:15p  | Closing Remarks   | Paige Nues, Director, Family Support, <i>IRSF</i>   | Colorado Ballroom                |
|                      | 8pm    | "Silent Angels" Movie Night   |   | Executive Press Room/Ampitheater |
|                      |        |   |   |                                  |
| <b>Monday May 31</b> | 9am    | Crackerbarrels: Learnings and Takeaways   |   |                                  |
|                      |        | Groupings by region: East, South, Midwest, Rocky Mountain, West   | Leslie Greenfield, Deborah Jennings, Shannon Stoiber, Heidi and Rhett Burnham, David and Melissa Luntz                |                                  |
|                      | Noon   | Registration/Help Desk Bookstore and close  |   | Foyer and Boardroom              |